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Providing answers to respiratory patients' questions during covid-19

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Viewpoint

Providing answers to respiratory patients' questions during COVID-19

The European Lung Foundation (ELF) brings patients and the public together with respiratory professionals to positively influence lung health, and regularly provides reliable information that has been co-produced by patients and professionals (from the European Respiratory Society (ERS)) and is available in multiple languages.

COVID-19

The ELF team closely monitored the first reports of the novel coronavirus in China and first wrote an article on 27 January 2020. This was quickly followed up by a page on the ELF website with the basic facts and figures that were taken primarily from the World Health Organization (WHO).

It was clear that this disease would be of concern to respiratory patients and it was agreed that a system should be put in place where patients could ask questions and have these answered by an expert.

Developing the resources

Initially an email was sent out to the patient organisations that are part of the ELF network [1] to ask if they were aware of questions that patients had. In parallel, the ELF team started to collate questions that they thought may be important for respiratory patients. On 3 March 2020, ELF contacted Professor James Chalmers, an ERS expert

in infectious diseases, to ask whether he would be willing to answer a few of our enquires so they could be added as a question and answer (Q&A) section on the website; he agreed.

After publishing the first Q&A, questions started to flood into our inbox. Between 6 March 2020 and 19 June 2020 we received 875 questions. The team were unable to answer these all directly, so an automated response was set-up to acknowledge receipt and direct them to the Q&A where their questions would be covered. Questions had their personal identifiers and specific information removed to leave the core question: *e.g.* "I have bronchiectasis, am I at higher risk if I catch COVID-19?". These were then sent to Prof. Chalmers and posted onto the ELF website in the form of a Q&A, which was updated weekly.

Concurrently, some ERS members got in touch with ELF to ask whether we had a resource for them to signpost patients to as they did not have the capacity to respond directly. They too used the Q&A for this purpose.

The challenges

With a small ELF team, February, March and April were challenging, but rewarding. The process of developing the Q&A with Prof. Chalmers and other ERS experts in specific areas helped the team understand the issues that patients were concerned about, and allowed them to keep up-to-date and

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 @ERSpublications

Quickly publishing questions from people with lung conditions, answered by experts in multiple languages, provided a well-accessed source of evidence-based support for individuals across the globe during the first wave of the #COVID19 pandemic <https://bit.ly/2F5ZP4k>



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informed about the information that was available. There was a real worry that patients had no one to turn to during this period, and the need for evidence-based information was evident.

Rapidly developing situation

Answering questions about COVID-19, especially in the early stages, was difficult as there were often no clear answers. The lack of clarity for the public and people living with lung conditions led to increased anxiety about the disease, which was evident in the types of questions that were being asked. As more information was gathered, the advice evolved and changed on a regular basis. This made it difficult to keep the website up-to-date and some information could not be posted as it evolved too rapidly to provide a useful picture for the public.

Different situations in different countries

The questions received by ELF came from many countries and continents, which meant that the challenges and government guidance were often different. The answers were checked to ensure that they could apply to all of Europe.

Need for different languages

ELF produces materials in nine core languages, but factsheets in up to 22 languages. The COVID-19 Q&A needed to be in as many languages as possible, but there were budgetary constraints. 11 languages were chosen: English, French, German, Italian, Spanish, Polish, Russian, Greek, Portuguese, Turkish and Persian. These included core languages and languages that volunteers came forward to help with. The translations were processed and uploaded weekly.

Making it visible

ELF promoted the Q&A through its newsletter, email lists and social media. It was also included as part of the ERS COVID-19 resource centre and promoted in the ERS newsletter. The total number of unique visits to the ELF website from 1 March to 13 July 2020 was 852 194 compared with 464 594 in the same period the previous year. 308 696 of these sessions were driven by the COVID-19 Q&A.

The evolution of COVID-19

What has been interesting has been the evolution of the questions and where the questions have been coming from over the course of COVID-19.

The questions asked

Initially the questions were more generalised and either focused on the disease, or the increased risk that underlying lung conditions might pose, for example: "I have sarcoidosis, am I more at risk of severe illness if I catch COVID-19?" or "I have asthma, am I more at risk of catching COVID-19?".

People were fearful that they would die of the disease and directly asked if this would be the case. There were concerns about shortages of ventilators and whether having a pre-existing condition would mean that a "healthy" person would be prioritised over them.

Fears arose from stories in the media, *e.g.* people with asthma fearing their steroid inhaler might make them more susceptible to the disease. Some were altruistic and asked whether their noninvasive ventilation equipment could be adapted and used for ventilation for others.

As time moved on, and more people had contracted COVID-19, the questions evolved to concerns about family members who had the disease and whether they would recover or whether the symptoms a person was experiencing could be COVID-19.

Along with questions about the long-term health effects of COVID-19, some people asked questions about symptoms that they were experiencing months after having the disease. As lockdowns eased, the questions became more focused on local guidelines, wearing masks in public spaces, shielding and how people who are vulnerable can start return to work.

The places the questions came from

We have seen geographical variance throughout the pandemic, initially most questions were from native English-speaking countries, as were visitors to the ELF website pages. As the questions were translated and there was increased awareness, the visitors to the COVID-19 pages diversified. In total, people from 227 countries and territories have visited the website over the course of the pandemic; the top 20 of which can be seen in figure 1. The countries with the largest number of visitors were the UK and the USA with 92 735 and 45 170 users, respectively, for this period.

As the visitors from other countries increased, so did the questions. Once the first wave in Europe had subsided, Mexico became the country with the fastest growing number of visitors, along with peaks from Argentina, Venezuela and Ecuador. This increase in access from South and Central America coincided with a peak in the questions being received from these areas.

Other resources

ELF produced a range of resources over the course of the pandemic, including the ability to share

experiences and stories, lay reviews of the latest scientific papers in the field, videos from experts answering specific questions about the pandemic, and factsheets on a range of issues (including what to expect if you are hospitalised and looking after your mental wellbeing) [2].

Many national and pan-European groups have also developed fantastic COVID-19 materials, and we have tried to act as a hub for these materials and for surveys and other activities being carried out over the course of this pandemic.

Conclusion

At the time of writing (August 2020), it is clear that many questions need to be answered about what the long-term impact of COVID-19 is. Are COVID-19 patients going to develop long-term respiratory conditions? Will rehabilitation be required? Will global lung function levels be impacted? Why are different groups more adversely affected? When will there be a vaccine, and will it be safe for respiratory patients?

It is clear from the success of this ELF initiative that patients and the public value access to reliable information, and particularly value the interactive nature of the Q&A format. These resources need to respond to the needs of those wanting answers and need to consider different aspects, such as the ever-changing status of information available and maintaining public confidence and managing concerns while dealing with rapidly evolving information. It is also vital to be able to offer resources in different languages.

For ELF, this has been an opportunity to work closely with the public, patients and patient organisations across Europe, and with healthcare professionals on the front line of the pandemic. The partnership between ERS and ELF has proved invaluable during this time.

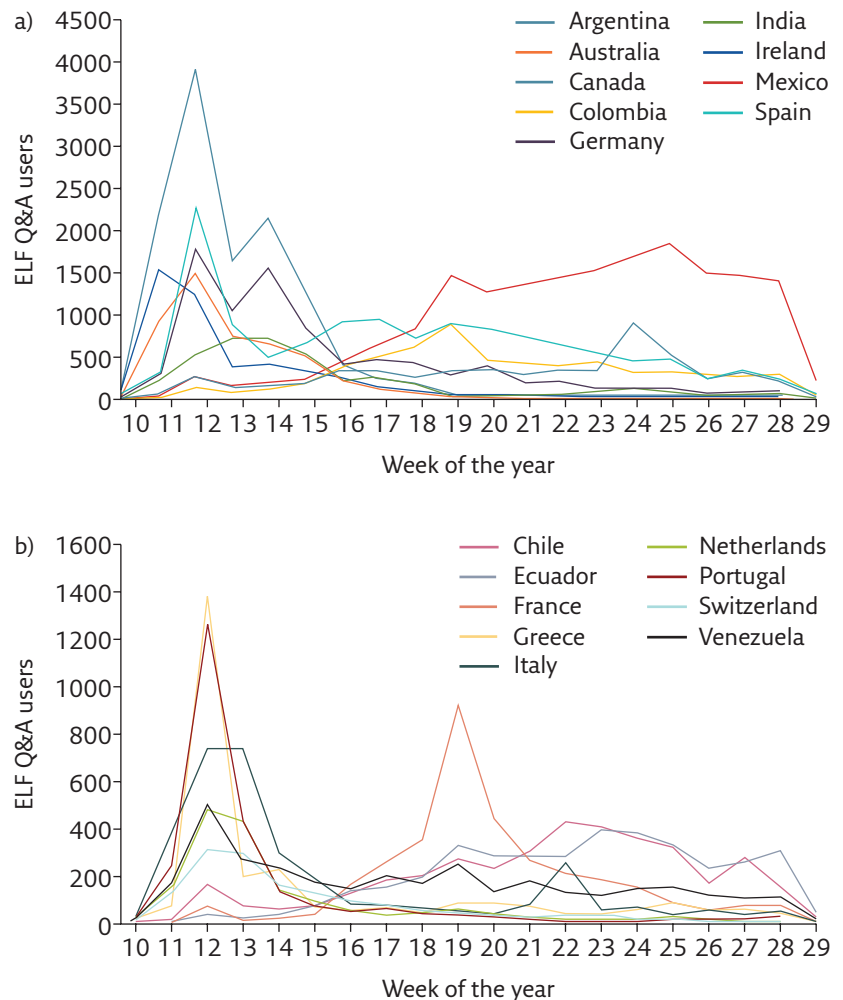


Figure 1 Two line charts displaying the countries with the highest numbers of users of the ELF Q&A webpage (the UK and USA have been removed to show the other countries in more detail) in the period 1 March–13 July 2020: a) countries ranked 3–11; b) countries ranked 11–20.

We have learned valuable lessons during the pandemic which will inform future approaches to supporting respiratory patients.

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Conflict of interest

J. Denning is an employee of the European Lung Foundation. P. Powell is an employee of the European Lung Foundation. J.D. Chalmers reports grants and personal fees from AstraZeneca, Boehringer Ingelheim, Grifols and Insmmed, grants from Gilead Sciences, and personal fees from GSK, Chiesi, Napp, Novartis and Zambon, outside the submitted work.

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